

Maryland Comprehensive Cancer Control Plan

SURVEILLANCE CHAPTER

I. Surveillance

1. What can surveillance do?
Describe the benefits of surveillance
The whole cancer plan is a testament to the value of data; past plans were used to influence policy and programming
2. Ideal Model- Show fluidity of data, feedback loop
-Chronic Disease Epidemiology (1998, Figure 3-1, p.56)
3. What is it?
CDC definition
Components: Indicator development, collection, analysis, dissemination.
4. Case examples of:
 - ** Local decision-making (data for local policy makers)
 - ** Health services improvement (breast cancer example)
 - ** Etiology investigations
 - ** Policy development
 - ** Use of CTR at Registry and subsequent audits of PG hospitals
 - ** Environmental example

Case Study: Surveillance for Cancer Programs Development

Surveillance Information:

- ❑ Maryland ranked among the top ten states in cancer mortality (decades)
- ❑ SAMMEC: Smoking Attributable Morbidity, Mortality, and Economic Costs (\$1.5 billion per year in MD)
- ❑ Tobacco is the #1 factor in the cause of cancer and heart disease (McGinnis and Foege, 1993)

State, Local or Community Action:

Maryland joined with other States in the legal suit against the tobacco industry and won

The Results:

Maryland Cigarette Restitution Fund Award Legislation

- Tobacco Use Prevention and Smoking Cessation programs
- Public Health Cancer Grants
- Academic Health Centers Research Grants
- Tobacco crop conversion program

II. Surveillance Efforts in Maryland: “Data rich, data smart”

1. Existing resources:

- Available data - description and summary 1-2 paragraphs about each data system and one overall table of key information about the database. Include examples of success and current uses for data.
- Cover the basic categories of cancer cases, deaths, risk factors, lifestyle behaviors, and access to care measures, and health care.

2. Gaps/ “Opportunities for enhancement”

Identification of indicators

- New/better variables for vital status/survival
- Occupational status
- Tobacco on all forms?
- Length of residency

Collection

- General lack of data about local, ethnic and racial disparities
- Data quality improvement (e.g. ACOS certification, training for TRs)
- Expand survey reach
- Sample size limitations in the Maryland BRFSS for some analyses (what counties need over-sampling?)
- BRFSS is English-speaking only (DM) and telephone respondents
- No QA assessment of cause of death information e.g. misclassification errors (?need for small pilot to assess need for broader assessment-may well be an issue for cancers such as prostate cancer – one study has suggested that a high proportion of “prostate cancer deaths” may have been to other primary causes) (DM)
- Exploration of potential uses of administrative datasets to assist in cancer prevention and control efforts (DM)

Analysis

- Coordinated approaches to analysis.
- Streamlined and efficient strategies for analysis and sharing of data.
- General lack of assessment of local, ethnic and racial disparities
- Technical assistance for LHDs and others
- Expand analyses- Quality of care, qualitative studies of NES population
- Prospective studies?
- Special studies, especially of the environment, risk factors, and lifestyle, using geocoding
- No annual BRFSS report for the state (only reactive to information requests) (DM)
- Calculation of cancer survival rates by stage (DM)

Interpretation and dissemination

- Broader dissemination needed.
- General lack of data and assessment of local, ethnic and racial disparities
- Technical assistance for LHDs and others

3. Data needs identified from other chapters

III. Recommendations

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Generate a list of “leading cancer indicators” for the State of Maryland and develop a plan to obtain them.

Designate a set of leading indicators – those that will, if changed, mean a change in cancer events (Kuller). This important list would guide not only Maryland data collection but also be linked to policy and program development. (NK)

Explore utility of using other data sets for surveillance (e.g., Medical Assistance, Medicare, HCACC) to answer surveillance questions (DD)

Standardize the use of race and ethnicity variables for all cancer-related databases to facilitate assessment of racial and ethnic disparities in Maryland across all databases. This will ensure that these data are collected and give some uniformity to the categories of race used. The Census Bureau values are a convenient standard and offer great flexibility for grouping in broader groups. (NK)

Develop system for evaluating quality of care among cancer patients for selected cancers (SN)

Designate a few “avoidable” cancer events which can be used as sentinels of problems in the delivery of cancer prevention and control. These events might include cervical cancers and cancer deaths, kidney cancers, and late stage breast cancers. (NK)

Continue quality improvement strategies in individual cancer surveillance systems, methods which improve or maintain completeness, timeliness, and validity.

Evaluate quality of cause of death information from death certificates (SN) Determine whether mortality data needs improvement (DD), i.e., analyze quality of death certificate data.

Encourage the development and implementation of QA/QC methods for all cancer-related databases. QA/QC is currently not done for many cancer-related databases. Maximizing validity and reliability of reporting is important. Other criteria for “evaluating” surveillance systems which may be used are found in the CDC article... (NK)

Establish mechanism for capturing BRFSS data from minority/non-English speaking populations (special survey, over sampling?) (SN)

Conduct ongoing expanded cancer behavioral risk factor survey and make data available on-line (DD)

- maintain funding for enhanced cancer BRFS
- have data placed on Web utility with BRFSS

Improve quality of cancer data elements submitted to the cancer registry among selected reporting facilities: (SN)

- Increase number of ACOS-approved facilities in MD, especially in PG county and other larger facilities without a tumor registry.
- Increase training for tumor registrars
- Increase number of Certified Tumor Registrars in MD

Continued enhancement of completeness, timeliness, and quality of the data in the various components of the surveillance system. Development of a phased approach for continued evolution and for “infrastructure development” of the surveillance system is advisable with priority given to those areas where incomplete, untimely, or poor quality data have the most impact on the usefulness of the data or on the ability to meet the information needs of the primary end-users (i.e. Policymakers (in and out of government), the Legislature, and advocacy groups). **Examples of incomplete data listed under “gaps” (DM)**

Develop expanded strategies to identify and investigate avoidable cancer events and unexpected occurrences in specific populations.

Create a surveillance resource that would design and routinely implement prospective, creative, and effective methods for cancer tracking. For example, for a specified set of cancer indicators, at every update with a new year’s data, observed and expected numbers of cancers would automatically be generated for counties by gender and race over time. Appropriate alert levels would be set. A protocol for action/reaction to these findings would be written and used. Another example, would include development of standard tables; these might include ten year rates by site, analyzed for trend and magnitude, relative to the U.S. **(NK)**

Develop a cancer inquiry program for the State **(SN)**

- Hire coordinator/consultant
- Develop cancer inquiry protocol
- Create cancer inquiry ad hoc committee to review selected inquiries
- Develop/listing of sentinel events (i.e., cervical cancer deaths) and mechanisms for flagging and incorporation into program planning
- Geo-code registry data for small area analysis

Perform “case investigations” on certain reports of cancer or cancer deaths **(DD)**

- determine which cases warrant “investigation” and what questions need to be answered
- get funding and IRB approval for investigations
- develop questions to be answered **(DD)**

obtain datasets for analysis

Develop “cluster” investigation procedures **(DD)**

- determine thresholds for ongoing prospective surveillance to identify “clusters”
- adopt methods and identify personnel for cancer “cluster” investigations
- broaden academic and laboratory support for investigating “clusters”

Determine thresholds for ongoing prospective surveillance to identify increases in specific cancers or specific cancers in specific demographic or geographic groups **(DD)**

Development of resources and approaches for dealing proactively or reactively with inquiries about incident cancer cases (i.e. “cancer clusters”). Activities might include development/enhancement of: **(DM)**

1. **Knowledge and Training** needed to respond to an inquiry about increased cancer risk. Areas include:
 - Statistical measures such as rates and proportions, age-adjustment and standardization of rates;
 - Statistics, including small area analysis;
 - Cancer data issues such as completeness, timeliness, and quality;
 - Cancer epidemiology and biology, including cancer in children;
 - Cancer screening opportunities;
 - Dealing with the media;
 - Interview techniques for clarifying and understanding the nature of the cancer inquiry; and,
 - Adaptation of CDC’s Guidelines for Investigating Clusters of Health Events specifically for cancer and for Maryland;
2. **Databases useful as resources**
 - desktop ready versions of cancer incidence and mortality
 - US national data sources that support environmental public health surveillance, such as the National Health Interview Survey, the National Exposure Registry, Water Data Storage and Retrieval system, and others

- "cluster logs" and applications to track cancer inquiries and disposition
- NCI CancerNet that includes PDQ information
- A national clearinghouse of cancer cluster investigation reports
- 3. **Software applications**
 - query tools such as CanQues, HIRS, or SEER*Stat
 - analytic tools for small area analysis and geographic area analysis
 - monitoring cluster reporting
 - geographic information systems
- 4. **Public education materials**
- 5.
 - risk and health communications
 - cancer screening opportunities
 - American Cancer Society support groups
 - NCI CancerNet that includes PDQ information for patients
- 6. **Organizational requirements** for implementing
 - protocols for responding to cancer inquiries
 - State vs local vs Federal roles
 - Advisory Board
 - communications infrastructure and Internet access
 - public affairs
 - laboratory support
 - intra-state departmental roles and staffing

Create a surveillance research agenda and a plan for implementation that engages a range of participants including the academic health centers, DHMH staff, policy makers, etc. and a range of issues: etiology, methodologies, descriptive assessments, unique local issues, racial and ethnic disparities, program evaluation, and others.

An over-riding priority of the surveillance system should be to increase the **applied** use of surveillance data for actual, real-world prevention and control of cancer. (DM)

Increase utilization of cancer registry data for program planning, evaluation and research. (SN)

Work with academic partners to develop scientific reports that shed light on specific cancer problems in Maryland. Develop a series of investigations that are published as journal articles or DHMH monographs. Create and use a distribution list for these reports; post on the Web. (NK)

Assistance from state agencies and academic centers in analyzing local data, compiling county-specific data books, including trends over time, directing further studies or collection of additional data (CL)

Develop a guide for database managers and analysts to use in assessing rates differences and trend in groups with small numbers. (NK)

Commission development of statistical methodologies to address small numbers issues and assessment of disparities for use by local and State health agencies in surveillance reports. The goal of these methodologies should be to maximize both information and privacy. (NK)

Conduct research into risk factors, etiology, outcomes, and knowledge, attitudes, and behaviors of both public and providers (DD)

- encourage CRF-funded research on surveillance-related projects
- seek additional funding for research

Another priority for the surveillance system should be to support other parts of the Center, Department, and government in cancer program planning, cancer program development, and cancer program evaluation: e.g. evaluation of sensitivity and specificity of screening programs; evaluation of population targeting of screening programs; effectiveness of early detection programs; effectiveness of outreach programs; costs of care; cost-savings from prevention/early detection; There may be unmet operational or scientific needs that should be addressed in the Plan to be able to adequately fulfill this role. (DM)

Make Maryland-specific, descriptive and analytic cancer reports and data readily available to those interested in cancer.

Increase Internet access to cancer reports, interactive cancer statistics, and downloadable public use cancer files. Post all annual cancer reports from DHMH databases coincidentally with published reports. Expand current DHMH interactive access to cancer-related data (e.g., BRFSS). Develop criteria for public use files, obtain IRB approval, and develop a mechanism for downloading or purchase. (NK)

Develop a Bloomberg Box for reporting cancer events. An immediate feedback loop would inform and motivate those interested in cancer prevention and control. (NK)

The Center can play a key role in improving the availability of timely, high quality information derived from cancer surveillance to a wide range of information users including the general public, media, lawmakers (and their staffs), policymakers, advocates, and the scientific community. Products and services that would enhance the capacity to fulfill this role could be identified: e.g. interactive, web-based databases query systems (with adequate controls for confidentiality) for cancer incidence, mortality, and/or risk factors (such software systems already exist and could be adapted specifically to Maryland but would require new resources in terms of staff time, servers, etc; development of downloadable general public use databases). (DM)

Develop system for conveying information on sentinel events to LHDs

Conduct ongoing expanded cancer behavioral risk factor survey and make data available on-line (DD)

- maintain funding for enhanced cancer BRFS
- have data placed on Web utility with BRFSS

Data collection, analysis, and communication methods appropriate to local needs (CL)

Consider the surveillance needs from each area of the MD Comprehensive Cancer Plan as the other surveillance recommendations are carried out.

Review needs from other committees to guide recommendations (SN)

A clear priority for the surveillance system (broadly defined to include registry, vital stats, BRFSS, special studies, administrative data, etc) should be to support the other parts of the Cancer Control Plan i.e. to be sure that all the data is collected that will be needed to assess the baseline, to demonstrate progress over time, and ultimately, to evaluate the success of implementation of the Plan (DM)